MIDDLE-AGED CAREGIVERS: AN EXPLORATORY STUDY OF THREE COHORTS

by

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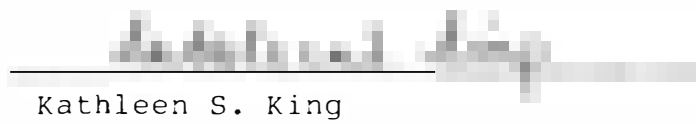
10 1 88 

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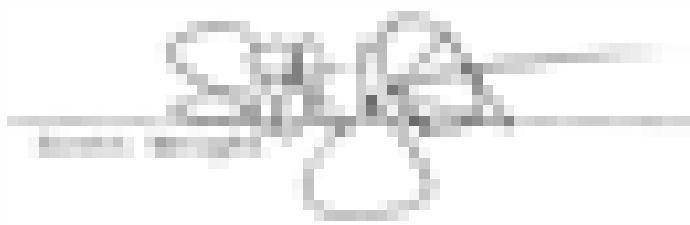
10.1.88 

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To the Graduate Council of The University of Utah:

I have read the thesis of Margaret Sobczak in its final form and have found that (1) its format, citations, and bibliographic style are consistent and acceptable; (2) its illustrative materials including figures, tables, and charts are in place; and (3) the final manuscript is satisfactory to the Supervisory Committee and is ready for submission to the Graduate School.

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ABSTRACT

A large, cross-sectional survey of caregivers to dementia patients provided the data base to study the effects of caregivers' age on the dependent variables of caregiver income, marital and employment statuses, their depression level, perceptions of burden, life satisfaction, number of persons in support system, and the functional level of the dementia patient. The sample consisted of 180 female caregivers between 35 and 64 years of age who were identified from support groups located in the Western half of the United States. Using the Pearson *r* correlation coefficient as a statistical measure of the variables under study, an inverse relationship was demonstrated between caregiver age, income, and employment. No significant correlations existed between caregiver age and the other variables under study. After dividing the sample into their age cohorts (35-44, 45-54, and 55-64 years of age), further data analyses using ANOVA failed to reveal significant age-related group differences based on the major dependent variables under study. With the small number of dependent variables used to study age, the results of this study are inconclusive.

This thesis is dedicated to my mom and dad, Rosella and Ed, and to my brother and sister-in-law, Ron and Geri. I give to you my heartfelt "thanks" for the care, love, support, and letters from home that have sustained me during the past 3 years.

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ACKNOWLEDGMENTS

I would like to acknowledge Dale Lund, Ph.D., Principal Investigator, for allowing me to participate in this study of caregivers to Alzheimer's patients. I would also like to acknowledge Ann Hutton, Scott Wright, and Kathy King for their challenge and support in writing this thesis.

CHAPTER I

INTRODUCTION, PROBLEM STATEMENT, AND PURPOSE OF THE STUDY

Introduction

In spite of the quantity of descriptive research on the concept of "women in the middle," few researchers have addressed the relationship of caregiver age to the experience of the caregiving role. Are there age-related issues involved in the middle-aged woman's role of caring for a relative who suffers from dementia? For example, does the age of the female caregiver affect her perception of burden or level of depression?

The concept of "woman in the middle" was first explored by Brody (1981). In her conceptualization, the term refers to the precarious position of a middle-aged woman functioning within multiple roles such as wife, mother, daughter, homemaker, and grandmother, while attempting to act as the primary caregiver for an aging parent. In light of the dynamic nature of caregiving and the number of middle-aged caregivers responding to the needs of their own demented spouses, it is suggested that the concept of "woman in the middle" should be expanded to include middle-aged spouse caregivers. Spouse caregivers

may still be functioning as mothers and grandmothers while experiencing the burden of caring for a gradually-declining spouse. Thus, a part of the caregiving burden involves the loss of one's role as wife or mate.

In the past, societal influences on life events provided predictability by defining the events associated with given periods of human life. Current social trends demonstrate that life's mileposts are no longer limited by chronological age (O'Rand & Henretta, 1982). Contemporary practices of divorce, remarriage, late-life marriage, postponed childbearing, and early career entry have irrevocably altered traditional norms and role expectations.

Contemporary women are now faced with a range of family and work possibilities (O'Rand & Henretta, 1982). With new dimensions added to women's lives, a "woman in the middle" is challenged by the competing values of: (a) the family responsibilities of caring for an elder, and (b) her freedom to work outside the home, if desired (Brody, 1981). In future decades, the choices of middle-aged women will be evaluated to determine whether parent-care patterns change in response to the new societal norms or whether the traditional values associated with women's relationships prevail.

Background for the Study

Caregiving

Caregiving is a broadly-defined, all-encompassing concept. The word "caregiving" defines all those actions and events involved with ministering to the needs of another. Caregiving is more than the science of rendering nursing care. In the context of an elder relative, it involves providing for physical needs, while maintaining that person's dignity and personal integrity. Simultaneously, however, the caregiver must maintain family homeostasis and meet his or her own needs for personal fulfillment.

Women have traditionally served as caregivers for elder relatives. Three factors have been identified as contributing to women's predominant assumption of the caregiving role: (a) historically, women have performed nurturant tasks, (b) women have been thought to have stronger emotional ties to their families of origin, and (c) women have been viewed as having greater amounts of flexible, free time in their roles as homemakers (Horowitz, 1985). These traditional role expectations are being challenged by two contemporary social factors that may necessitate different patterns of caregiving in the future (Horowitz, 1985): (a) a trend toward smaller families with fewer children, and (b) an increase in the number of women in the workforce.

Family Caregiving

Problems associated with family caregiving for a sick, elder relative have come to the forefront during the 1980s. Changes in health care policies and financing have placed pressure on families to provide nursing care needs for their elder relatives at home. For example, in February, 1983, action was taken to reinterpret Medicaid policy in an attempt to reestablish filial financial responsibility laws (Horowitz, 1985). While this legal action might seem to suggest that families do not have a sense of personal responsibility toward their parents, in fact, parent-care has always been a traditional part of American family life (Brody, 1981; Cantor, 1983, Horowitz, 1985).

The real issue is not whether families desert their elderly ill or disabled relatives, but that individuals are living longer, with an increased likelihood of having a number of chronic illnesses requiring costly medical and nursing care. The United States Senate Special Committee on Aging predicted that by the year 2010, when the aging baby boomers are in their mid 60s, "an older society will be upon us" (1983, p. 1). In addition, the growing elderly population is supported by a much smaller population base of future caregivers (Treas, 1977).

As the burden upon families increases, individual family members will find it more difficult to obtain

quality care for their elder relatives, secondary to federal and state cost-containment efforts. Based upon the number of current aged and the predicted growth in that population, it will be useful to understand the nature of the stresses involved in the caregiving role so that nurses can be prepared to help prevent or alleviate existing problems.

Not all middle-aged caregivers experience the same degree of stress in caregiving. It is likely that some differences in caregiving are related to the age of the caregiver. For example, Stoller (1983) suggested that the impact of role demands may more easily be met by younger, working mothers. She stated that the older caregiver may be facing a task load which is greater because of

> ... familial responsibilities involving competing demands from several generations. The adult children of the elderly most in need of care may, themselves, be entering old age and facing these increased demands with depleting physical energies. Caring for elderly parents also may involve emotional burdens, since adult children must cope with anticipatory bereavement accompanying what may be irreversible declines in their parents' health and functional status. (p. 857)

This view of differences in caregiving experiences according to age contrasts with the view of all caregivers having similar experiences and homogeneous needs.

Differences among the experiences, needs, and perceptions of the younger and middle cohort of middle-aged caregivers have, however, not been documented. Since

involvement of family members in caregiving is rising, identifying differences in caregivers' experiences on the basis of age and other demographic characteristics will be useful in planning nursing care, as well as eventually impacting health care policy.

Developmental Life Stage

Developmental life stage is a concept that is used to identify individuals' positions on a maturational gradient at various stages of their lives (Turner & Helms, 1979). Cutler (1985) noted that caregivers may need help in separating their developmental issues from the stressors involved with caregiving. An example would be the female caregiver who is a young widow in her early 50s, with no siblings and no children who is now the sole caregiver to demented parents. She may evidence sarcasm and irritability with her parents but not understand the changes in her normally warm and competent personality. She would need help in separating the stresses of normal developmental issues in her life from the stressors of parent-care.

Rationale

Health care professionals are being called upon to work with family members in the delivery of home care in increasing numbers. Previous researchers have failed to determine if there are, indeed, age-related differences

among and between the three decades associated with middle age; and, if there are differences, whether these differences are indicative of unique responses to the caregiving role based on age.

Statement of the Problem

Previous researchers have suggested that caregivers, depending on life experiences associated with various ages or developmental stages, may encounter different stresses in the caregiver role. These differences have not, however, been systematically identified or studied. In this study, demographic characteristics of both caregivers and patients were described in order to determine whether there were significant associations between these variables and age of the caregiver.

Purpose of the Study

The purpose of this study was twofold: (a) to describe the relationship between caregiver age and the female caregivers' responses to the care required by relatives with dementia; and (b) to identify differences between caregivers in specific age cohorts and their response to care of their relative with dementia by examining caregiver demographic characteristics, perceived burden, life satisfaction, depression, number of individuals in the support system, and the functional level of the dementia patient.

CHAPTER II

REVIEW OF THE LITERATURE

The issues pertaining to age and caregiver burden can best be understood by exploring previous research and theory under the following headings: (a) demographics of the aging population, (b) chronic illness, (c) dementia, (d) functional assessment of dementia, (e) caregiving, (f) middle-aged development, (g) middle-aged women, (h) the burden of care, (i) support system availability, and (j) depression in caregivers.

Demographics of the Aging Population

By the year 2010, one quarter of the U.S. population will be at least 55 years of age and one in seven U.S. citizens will be older than 65 years of age (U.S. Bureau of the Census, 1982). Equally alarming is the rapid increase in the group of U.S. citizens over 75 years of age. In 1982, this group represented just 5% of the population. By 2030, those 75 years of age and older will represent 10% of the population and by 2050, this figure is expected to increase to 12%. Concurrent with this trend, it is expected that by 2050, those U.S. citizens 85 years of age and older will account for 5% of the total

population (U.S. Special Senate Committee on Aging, 1983).

These trends toward increased numbers of elderly in the U.S. population are often attributed to ever-increasing longevity. In reality, however, increased number of births prior to 1920 (accounting for present elderly) and the baby-boom generation of World War II (the future elderly) have made the most significant contributions to these trends. Improved mortality rates can only exacerbate these figures in coming years (U.S. Senate Special Committee on Aging, 1983).

Although the lifespan has increased, the percentage of an individual's life that is devoted to chronic disease has not decreased. It has been suggested that the number of chronically ill elderly will continue to increase for a number of years (Weiler, 1986).

Chronic Illness

Chronic disease has typically been defined by duration of illness (lasting greater than 6 weeks). Recent technological advancements have allowed medical science to overcome many of the major difficulties associated with chronic disease. Therefore, Fries and Crapo (1986) suggested that rather than judging chronicity purely on the basis of illness duration, a more realistic view of chronicity might center on its: (a) incremental nature, (b) universality, (c) clinical threshold, and (d) progressive loss of organ reserve.

Presently, 83% of those individuals over 65 years of age and older are afflicted with at least one chronic disease (Longe, 1986). With advancing age, the amount of functional limitation associated with chronic illness increases. Among those 65 years of age and older, 20% have difficulty performing activities of daily living (ADLs) (Longe, 1986). As the difficulty with ADLs increases, there is an increased need for assistance from caregivers. Dementia is one chronic illness of age that causes profound change in all functions of the human species, thus necessitating significant assistance by caregivers.

Dementia

As defined by the American Psychiatric Association (1975), dementia is

> ... an irreversible mental state characterized by decreased intellectual function, personality change, impairment of judgment and often change in affect, due to permanently altered cerebral metabolism (Smith & Kinsbourne, 1977, p. 10)

Wang (1977) listed three components of dementia: (a) memory deficits with attendant cognitive dysfunction, (b) associated neuropathologic changes, and (c) clinical manifestations secondary to cognitive impairments.

The most common of the dementing illnesses is Alzheimer's Disease. The presentation of this illness is such that it might be considered a mental disorder. The Diagnostic and Statistical Manual of Mental Disorders (DSM

III) (APA, 1987) states,

> . . . that Alzheimer's disease itself is a physical disorder, and therefore, is not included in this manual of mental disorders . . . (p. 119)

This disease is currently irreversible and progressive, resulting in both extreme memory loss and functional disability. While Alzheimer's Disease affects a small percentage (5%) of those 65 years of age and older, the degree of physical, mental, and emotional devastation to the client is radical with far-reaching effects on the patient's family and caregivers (Scott, Roberto & Hutton, 1986). Folstein, Powell, and Breitner (1983) noted that the symptoms of Alzheimer's Disease have five progressive stages: (a) memory loss, (b) loss of powers of reasoning, (c) decreased comprehension, (d) deterioration of personality, and (e) a final vegetative state.

Over 3 million U.S. citizens over the age of 65 are affected by Alzheimer's Disease (Ebersole & Hess, 1985). Due to the advancing age of the population, the number of persons with Alzheimer's Disease is expected to increase over 50% over the next 25 years, providing there are no major advancements in the prevention and treatment of the disease (Mace & Rabins, 1982).

Functional Assessment of the Dementia

The major functional problems that a caregiver can expect with a dementia patient are: forgetfulness,

agitation, wandering, emotional lability, and in the later stages, incontinence and greatly impaired intellectual function (Ebersole & Hess, 1985). Families of dementia patients are able to manage the care of their family member via the extensive use of support services (Moore, Bobula, Short & Mischel, 1983).

In order to adequately provide these services, it is necessary to ascertain the degree of functional limitation that the patient is evidencing and with which the family must cope. To meet this need, researchers at Duke University (Moore et al., 1983) developed the Functional Dementia Scale (FDS). The purpose of the FDS is to determine functional limitations, while identifying both level of impairment and level of assistance needed (Ebersole & Hess, 1985).

Caregivers

Adult daughters often assume the role of caregiver to the ill parent or family member. Developmental theorist Carol Gilligan has proposed that women may respond to caregiving needs more readily than men as they are more sensitive to relational matters than men (McLoughlin, Shryer, Goode & McAuliffe, 1987). In the caregiving role, the daughter or spouse becomes the sole source of physical, emotional, social, and economic assistance to the chronically ill, impaired relative (Brody, 1981; Masciocchi, Thomas & Moeller, 1984; Stoller,

1983). Additionally, the family member requiring long-term care often lives with the caregiving family (Masciocchi et al., 1984).

The dynamics of becoming the primary caregiver have been addressed in several research studies. Cath (1972) suggests "closeness" is not essential to task assumption. However, Cantor (1983) noted that a sense of closeness to the ill person is often a precursor to the assumption of task responsibility. Cath suggests the female adult child may simply designate herself or be designated by the family as the primary caregiver for the impaired parent. Among those choosing this role, some may use the position to reconcile past parent-child estrangements. Cath (1972) noted that it may be the least loved of the children who is motivated to assume the caregiving role, and caregiving may be used to alleviate guilt or gain parental favor by maneuvering others away from the role.

"Closeness" may imply assumption of the caregiving role and it may also be a predictor of the amount of strain to be experienced (Cantor, 1983). A proportionate, inverse relationship between closeness of the caregiver and the care recipient and the ability to get along has been demonstrated (Cantor, 1983).

Emotional strain is pervasive throughout the caregiving family with children being as affected as spouses and other relatives (Cantor, 1983). The assump-

tion of elder care often results in the loss of "freedom, mobility, energy, and time" (Masciocchi et al., 1984, p. 21). The primary caregiver who has a great sense of family responsibility toward other family members experiences a deeper involvement.

"Familialism," a term coined to describe a deep involvement with the family, is viewed by many as a predictor of stress (Niederehe & Fruge, 1984). Cantor (1983) asserted that the greater the sense of family and cohesion, the greater the likelihood of strain in the caregiving relationship.

The burden of caregiving can be quite overwhelming. No caregiver age is free from strain. When reporting a high rate of psychiatric distress among caregivers of Alzheimer's patients, Niederehe et al. (1983) noted that younger caregivers, compared with spousal caregivers, generally evidenced more severe stress. Adult child caregivers who are approaching retirement age may find they are experiencing increased demands with less than optimal energy reserves available for the task. They are also faced with the emotional burden of coping with anticipatory bereavement for the patient, as well as anticipating their own mortality (Stoller, 1983).

Cantor (1983) and Stoller (1983) studied how caregivers cope with the rigors of everyday existence, above and beyond the multiple demands of caregiving. Both

investigators noted that although household standards were lowered, tasks were performed. In cases where the caregiver participated in employment outside the home, the female caregiver continued to function on the job. Furthermore, these caregivers maintained positive relationships within their families by devoting adequate amounts of time to maintaining these relationships. The greatest deprivation experienced by the female caregivers was in the areas of personal individuation and opportunities for socialization (Cantor, 1983).

Thus, evidence demonstrates that women do carry on with the operational tasks of life in the face of many obstacles. To fully understand women's response to the caregiver role, it is valuable to identify the challenges of the developmental phase of the middle-aged female.

Developmental Issues of Middle Age

Human development is viewed on an age-based continuum (Goldhaber, 1986). Although this view fails to explain the way in which people behave, it is the accepted standard by which they are measured for their developmental stage (Goldhaber, 1986). This standard is termed stages of development.

Levinson (1978) developed a stage theory for adult male development. The first stage of the adult male cycle lasts from 18 to 45 years of age. During early adulthood,

men leave home, develop an adult self-image, make an initial then permanent vocational choice, marry, and start a family. Levinson placed middle adulthood between the early 40s and the mid 60s. At the beginning of this period, men appraise their accomplishments in life and then readjust these goals. At this point, men reemphasize bonding to their family and to relationships. Their employment is deemphasized. During late adulthood, these same men, again, take stock of their positions and consequently reprioritize their lives.

Frieze (1978) developed a stage theory of adult female development. The pattern of human development for women differs from that of men in two respects: first, the primary focus of life is the home and family versus occupation; and second, it is more complicated than that of men. Women cannot relegate selected aspects of their life to the "back burner." Women are equally concerned with work, intimacy, and family.

Frieze (978) identified three phases in women's development:

1. Phase 1: Leaving the family. the woman's goal is psychological emancipation from parents and the formation of an adult life plan. A balance is worked out between marriage and a career. The husband's career takes precedence in mediating what a woman does during this phase of her life.

2. Phase 2: Entering the adult world. Women who marry, have children, and a career experience a heavy burden. Attempts to equally meet their needs for work, intimacy, and family are complicated by the socialization patterns and role modeling of males in modern society. Husbands/fathers rarely pursue a significant assumption of the workload within the home/family. Much of the responsibility for "home" maintenance falls to the wife/mother. This responsibility is so burdensome as to cause the female to frequently fall out of her career until the children are older and in school.

3. Phase 3: Entering the adult world (again). A woman in her early 30s is able to define herself as an individual and not as someone's wife, mother, or daughter. At this point, women increasingly commit to a career. Ironically, it is at this time that men are recommitting themselves to the family.

The developmental tasks of middle age, as listed by Havighurst (1972) are: (a) assist teenagers' growth toward becoming responsive and happy adults, (b) actively partake in social/civic responsibilities, (c) reach a point of satisfaction with one's career choice, (d) develop leisure activities, (e) re-relate to one's spouse as a person, (f) accept adjustment to the physiological changes of aging, and (g) realign relationships with an aging parent. Havighurst asserted there was value in

attending to life's changes from a developmental perspective for two reasons. First, there is clarity about the basic expectations which a society holds of its members, and second, this activity informs a society of the basic services that individuals expect (1972).

Erikson (1950, 1968, 1980), in his theories of psychosocial stages, lists the developmental task of persons aged 35-60 as developing a sense of generativity. If this task is not accomplished, a sense of stagnation ensues. For those 60 years of age and beyond, it is important to achieve a sense of ego integrity. If the individual does not develop this sense of ego integrity, then there is an ensuing sense of despair. Erikson contends that a secondary task of each new task is the incorporation of the previous accomplishments into this new functional level (1980). He contends that there is a constant redefining of the past task accomplished in light of the new task undertaken. This identification of new tasks and redefinition of old ones can be viewed in light of characteristic markers in a middle-aged woman's life. The boundaries of midlife are now said to be 35-64 years of age (Brooks-Gunn & Kirsh, 1984; Long & Porter, 1984).

Middle-Aged Women

Brooks-Gunn and Kirsh (1984) suggest five possible markers that have been used to define midlife among women. The first is chronological age. Age is seen as a

signal of the physical, psychological, and sociocultural markers of change. Second, parenting status has reached a point where children are in their teens, or are young adults. Developmental literature frequently focuses on the cessation of active parenting that has been referred to as a woman's "midlife crisis."

The third factor identified by Brooks-Gunn and Kirsh (1984) is the change in a woman's work life. The focus is moving away from the in-home, mother-wife role toward an out-of-home employed woman-wife role. Currently, employment among women is at an all-time high: 66% of those aged 35-44 are employed, 60% of those 45-64 years of age are employed, and 42% of those falling in the 55-64 age group are employed (U.S. Bureau of the Census, 1981).

The fourth marker is one of an increase in relational demands (Brooks-Gunn & Kirsh, 1984). It has been asserted that during a woman's midlife, childbearing demands decrease while other demands (employment and community) increase. As childrearing demands decrease, there is a simultaneous increase in the relational obligations to older parents, grandchildren, and husbands.

The fifth and final marker of midlife is that of hormonal adjustment (Brooks-Gunn & Kirsh, 1984). Hormonal adjustment is occurring as menses begin to slow and cease altogether. The woman in midlife has new physiological experiences occurring at unpredictable moments. Heat

waves come without warning, as do the "sweats." Tissue that was formerly firm and resilient begins to sag and become friable. Sex, as the woman is freed from child-bearing concerns, may become more enjoyable, although it can also be more uncomfortable with the depletion of normal body lubricants. The changes of midlife herald the transition from young adulthood to a more mature adulthood leading finally to old age. In short, no aspect of a woman's physical, mental, or emotional self remains untouched by the hormonal aspect of midlife.

Researchers now recognize that all of these changes may not be normative. Increasingly, women are entering activities such as marriage, childbearing, and initiation/cessation of careers during developmental stages considered "off time" by norms of the past. These women are helping to establish the choices and norms for the future (Neugarten, 1977).

An emergent trend recognizes that middle-age is proceeding under new sociocultural norms (O'Rand & Henretta, 1982). People are able to conduct their lives, not according to a societal time frame, but from an individualized, more privatized perspective. Middle-aged women are now defined as both predictable and variable (O'Rand & Henretta, 1982). In order to understand a middle-aged woman's response, it is important to look at:

> (a) the appropriate referent group (or groups), rather than comparing individuals to societal

> norms that may not be salient to the individual (as in the example of urban teenage mothers); (b) women's perceptions of the timeliness of specific events ...; (c) the importance of others' beliefs about timeliness in determining an individual's reaction to a life event ...; and (d) the relationship of differing measures of timeliness to an individual's life satisfaction and feelings of effectiveness and self-worth. (Brooks-Gunn & Kirsh, 1984, p. 17)

Middle-aged women represent a diverse profile with the "baby-boomers," the followers of the Feminine Mystique, and the women of the Great Depression included among this contemporary grouping (Long & Porter, 1984). This cohort has also experienced a variety of life events, changes, disruptions in family life, increased participation in the workforce, and a revamping of priorities among multiple roles (Long & Porter, 1984).

Men at midlife are seen to have more control over the amount of time that family demands can make of them than are women in the same life stage. It is yet to be seen whether employment "excuses" women from relational tasks, particularly if their financial assistance is crucial to the family. Additionally, researchers have yet to learn whether employed women will ask their husbands to assist with family tasks versus taking total responsibility for both work and family (Brooks-Gunn & Kirsh, 1984).

The cohort of women currently defined as women in the middle is faced with societal demands for role change and adaptation that are among the greatest for any cohort to date (Masciocchi et al., 1984). The two emerging trends

of a rapid acceleration in the aging population and the increasing numbers of women in the workforce, plus new societal demands, have resulted in middle-aged women who are truly "women in the middle" (Brody, 1981).

The traditional value of women's responsibility for elder parent care adds an additional source of conflict (Brody, 1981). The vast majority of three generations of women (grandmothers, daughters, and young adult granddaughters) endorse the "traditional value of filial responsibility to the aged" (Brody, 1981, p. 475). According to Brody (1981), younger women are just as committed to caring for aged relatives as middle-aged women and elderly grandmothers. While older people believe they should be able to depend on their adult children for help, grandchildren are seen as satisfactory and reliable helpers (Brody, 1981). Granddaughters tend to feel more strongly about their responsibilities to their grandparents than their mothers (Brody, 1981). While the attitudes of younger women are said to reflect a lack of experience and idealism (Brody, 1981), they should not be cast aside as they represent important resources for present and future elder parent-care concerns, as well as for spousal care among the future elderly.

Women in the middle are represented by a wide range of ages and life experiences. A woman in the middle may well occupy the second or third position in a four-

generation family. The third generation may be responsible for their children, as well as two generations of older people (Brody, 1981).

The boundaries of midlife may have moved to an older age for some of the following reasons: (a) a more protracted young adulthood, (b) the relative good health of today's midlife woman, (c) the experience of enhanced sexuality for many women, (d) the experience of midlife at a time of active parenting, and (e) the change in life expectancy and the subsequent alteration of the boundaries of midlife. For example, if one views old-age as the last 15 years of life, the boundaries of midlife must expand with the increased life expectancy of people in general. After all, since old age still carries a stigma, no one seeks to arrive at that stage too soon (Brooks-Gunn & Kirsh, 1984).

With middle-aged markers and society in rapid transition, it can be expected that both differences and similarities among middle-aged women will be manifested.

Differences and Similarities Among Middle-Aged Women

Midlife transition, at times referred to as an "in-between stage" occurs between early and middle adulthood and between the ages of 38 and 48 years (Johnson & Irvin, 1983, p. 119). During this time, there is an expectation of increased leadership within the extended family. This

expectation is accompanied by a tallying of all that has been accomplished in life to that point, while recognizing that youthful dreams either have or should have been achieved at this point. Youth is recognized as lost and the potential for death is more real than it has ever been (Johnson & Irvin, 1983).

Midlife means many things to many people. To some, it is a time of welcomed freedom and mobility. For others, the increased time and freedom suggests a sense of loss of the parenting role (Johnson & Irvin, 1983). Women whose lives center around childrearing and who have relied upon it for a barometer of their usefulness and meaningfulness, experience depression, anxiety, and identity confusion as their adult children leave home. If there has been a well-covered marital problem, the absence of the child can cause it to resurface (Johnson & Irvin, 1983).

For many adults entering the transitional phase of midlife, there is the dual role of being both a parent and a child. This is critical because both parent and child are at a point in time in which they are assessing, aligning, and integrating some very fundamental issues such as body image, role expectations, and shifting self- and object representations. A great deal of turmoil is generated for the family. Both the adolescent and parent are highly vulnerable developmentally. The manner in

which these conflicts are resolved can result in dysfunction within the family system (Johnson & Irvin, 1983). Added to the many concerns of middle-age is the burden of caring for family members with dementia.

Burden of Care

The effects of caregiver burden on the primary caregiver are far-reaching. These effects touch all aspects of life: physical, mental, recreational, and financial (Ory et al., 1985). Niederehe et al. (1983) determined that cognitive abilities of patients are not correlated with subjective strain or impact of the disease upon the family. They also reported that frequency of patient negative behaviors and emotional symptoms were significantly correlated with both subjective strain and impact of the disease upon the caregiver (Niederehe et al., 1983).

Further, Zarit, Reever, and Bach-Peterson (1980) documented that caregivers experienced most burden in relation to lack of time for themselves, excess dependency of the family member on the caregiver, and fear of the ill family member's behavioral deterioration. Zarit et al. (1980) noted that none of the deficits (e.g., behavior, memory, cognition, functional disability, or illness duration) was related to perceptions of burden. Rather, it was noted that perceptions of caregiver burden were proportionately reduced by the number of family visits

into the caregiver's home.

Supportive family visits were also noted to be helpful by Billings and Moos (1984). In their study, the more supportive a family visit was, the more effectively reduced were depression and physical symptomatology experienced by the primary caregiver. When a primary caregiver's entire natural support system shares in the care of an elder, the burden appears to be somewhat reduced (Zarit et al., 1980). Social support considerably lessens caregiver perceptions of burden.

Social Support

The role of availability of supportive relationships in reducing or buffering the impact of stress on physical and emotional health has received considerable attention in the literature. The way in which individuals perceive their social support system may, in fact, offer protection from stress-related illnesses (Gottlieb, 1985; Hibbard, 1985; Schaefer, Coyne & Lazarus, 1981). These supportive systems are seen to serve as a protective buffer for persons confronted with distress. Caplan (1974) asserted that social support systems allow individuals continued opportunities for feedback and for validation from others. Wilcox (1981) noted that supporters provided emotional assistance, obtainable resources, information, and thoughtful guidance. The emotional support helped individuals master their own emotional problems via a

mobilization of psychological resources.

There are two components of social support: (a) instrumental support (e.g., bathing, cleaning, cooking, and day-to-day tasks), and (b) the emotional support of knowing that there is someone who understands the caregiver's experience and is willing to offer encouragement in times of difficulty. Support can either be informal (e.g., from family, friends, neighbors), or formal (e.g., social service agencies, health agencies, counselors) (Zarit, Orr & Zarit, 1985).

Several studies, including those by Barrera (1981) and Turner and Noh (1982), indicate that those who have more negative life events perceive a lower level of social support, as well as a decreasing sense of helpfulness from the support given (Aneshensel & Frerichs, 1983). Mitchell and Moos (1984), however, report that dramatic negative occurrences may not be the most disruptive, but that ongoing strains may be more problematic. Continuous burdens may both work against the individual's desire to maintain social ties and against the social network desiring to help.

The individual who experiences a greater strain in the caregiving role has less education and family support, and fewer positive experiences (Mitchell & Moos, 1984). Those with more severe depression have concomitantly more negative events and strains, fewer positive events, and

fewer close friends, with a diminished level of family support (Mitchell & Moss, 1984). The point at which caregivers chose to confide in others about these difficult experiences was related to increased problems in a number of areas (Niederehe et al., 1983). Niederehe et al. asserted that caregivers need to confide in others, although these confidences may not decrease the stressful experience.

Niederehe et al. (1983) also noted that less-trained caregivers reported greater use of emotional support. The less-trained were noted to keep the patient stimulated and involved in activities. Those caregivers who opted to use "reasoning" with the patient, as well as coercive techniques, were the caregivers with the greatest problems.

Observations were made of family members who had fewer relational difficulties and less difficulty with guilt reactions toward their family members residing in nursing homes (Wilken, 1986). These adult children were noted to share concerns and their lives with the family member residing in the nursing home. Communication was free of cute names or mannerisms and family members did not bring dolls or gimmicks to the confused parent. They spoke to their parents with respect and in a way cognizant of the fact that boundaries between the elder and themselves existed (Wilken, 1986).

Depression in Caregivers

Research has shown that at midlife, there is a greater vulnerability to depression among the general population (Gurland, 1958; Horn, 1970). Since the majority of caregivers are in middle-age (Brody, 1981), it is important to assess caregivers for possible symptoms of depression and to plan support with this understanding.

Evidence suggests that depressed individuals use different coping responses than nondepressed persons (Billings & Moos, 1984). Depressed persons seek out information and respond more emotionally when attempting to problem-solve a difficult situation. They also use problem-solving coping strategies less frequently than nondepressed individuals. Additionally, depressed persons are thought to have a distorted appraisal of the environment. The combination of diminished problem-solving techniques and pessimistic environmental appraisals may well exacerbate the depressive symptoms (Billings & Moos, 1984).

Grad and Sainsbury (1963) noted that caring for a person with chronic, dementing illness takes its toll on caregivers by bringing them to an emotionally low point. While feeling low has been attributed to the caregiving role, Horowitz (1985) noted that among caregivers, daughters were more likely than sons to undertake the caregiving role without the emotional support of their

spouses.

Depression among female caregivers was also studied by Fitting, Rabins, and Lucas (1984). They found that females had a significantly higher mean raw score on the depression subscale of the Minnesota Multiphasic Personality Inventory (MMPI) than male caregivers. These results are consistent with other epidemiological studies that have found that women, in general, report more symptoms of depression than men (Boyd & Weissman, 1982).

In a study of younger and older caregivers, Franks (1974) found that younger (< 67 years) caregivers were both unhappy and resentful about their caregiving role. Fitting and Rabins (1985) suggested that the difference reported by Franks could indicate that chronological age and life stage might be significant predictive variables for caregiver stress when coping with a demented person.

Becker (1980) noted that caregivers were often reluctant to admit the amount of stress they were experiencing. If sufficient time was spent with caregivers, they were less defensive and talked more freely about the stress they were experiencing. It was noted that the outpouring of feelings lasted only a short time, after which the caregiver would retreat into his or her initial position of minimization prior to the end of the discussion. The weighty nature of daily demands was thought to be so difficult as to require that caregivers

keep their internal resources available for the daily needs of the ill. Caregivers needed to suppress the full impact of their emotional turmoil in order to garner emotional reserves for their caregiving duties. This is important information for professionals who counsel caregivers. Working through depression takes energy, even for the depressed person who is not a caregiver. For the caregiver, however, energy is already being diverted by a situation that is highly demanding. Health care professionals must first recognize the tendency of the depressed caregiver to suppress adaptive coping. However, they must also remain cognizant of the fact that it may be important for the caregiver to maintain the denial or suppression.

Summary and Conclusion

There are psychosocial stages of development that occur throughout life. Maturation through these stages involves personal stress because the tasks inherent in the stage of middle age are unknown and need to be worked through. Unanticipated tasks or stressors that occur during a particular developmental stage may create an additional burden. They may prolong or make more difficult the resolution of the normative developmental task. Caregiving may be viewed as interfering with psychosocial development. It may lead to lower life satisfaction, depression, and perceptions of burden or

stress.

Research studies with women at midlife have shown a lack of fixed progression in task accomplishment. Past norms are changing. Physical and emotional difficulties associated with caring for aging parents, however, continue despite life's other challenges. The need for parent or spouse care occurs without regard for the new normative structure women are following.

The numbers of disabled aging parents or spouses are increasing due to past population increases, as well as advancements in medical technology. Parent or spouse care is becoming a normative experience, as is the prevalence of chronic illness among the elderly. In response to the high cost of acute care delivery, as well as the generally poor reputation of nursing homes, more families are choosing to care for their disabled relatives within the family's own home. Home care has now become long-term care.

Elder care, like all other household activities, is considered the domain of the adult, female daughter or spouse. Most of these female caregivers have little formalized nursing training. They find themselves charged with the care of a parent or spouse with a highly complex and insidious disease. The burden of care is often born without the benefit of wisdom or knowledge of either the caregiver's or the patient's needs. Frequently, it is

only when caregiving stress has escalated to a dangerous level that the caregiver's need for help is acknowledged by the family or the medical community.

Social support necessary for shouldering the burden of parent care is critical to the endurance of the task. Women are known to have a higher level of depression than men. Daughters and wives who are able to share the burden of care with family and friends are able to tolerate the difficulties with less depression and for a longer period of time.

Parent or spouse care is a complex and inescapable fact of life for many adult women. With the increase in the aging population, most adult women will, at some time, be involved in the caregiving role for their parents or spouses. Social support is of inestimable value. Health-care workers would do well to support adult daughters and spouses in their attempt to share the burden with other family members.

Conceptual Framework

Psychosocial developmental stages across the life span have been discussed as a framework for understanding potential differences in caregiving experiences of middle-aged women. Havighurst's (1972) developmental tasks theory is representative of this framework. Havighurst (1972) proposed that developmental tasks should: (a) express the basic expectation that society holds for its

people, and (b) state the mechanisms that society must put into place for these expectations to be met.

It is valid to ask, what criteria should society use to determine the basic expectations that it holds for its people? In 1980, Baltes, Reese, and Lipsett proposed a model of development reflective of multicausality in life stressing three interactive components: (a) normal age-related influences that are similar for most people sharing a similar culture (e.g., school); (b) normal life events influenced by history and associated with a particular point in history (e.g., the Great Depression, Vietnam War); and (c) the abnormal life events that are outside the realm of normalcy in the life cycle and that are not associated with chronological age or a particular cohort (e.g., divorce, accidents, or career changes). Thus, developmental theory was used as the framework for assuming that there might be age-related associations and/or differences in middle-aged women's perceptions of their caregiving experiences.

Conceptual and Operational Definitions of Variables

The instruments employed in this investigation are addressed at length in Chapter III. The following conceptual and operational definitions briefly address the instruments and concepts used for this study.

Caregiver

A caregiver is the person providing assistance and support to a demented patient who is unable to be self-sufficient in meeting daily self-care needs.

Middle-Aged Caregiver

For the purposes of this study, the term "middle-aged" caregiver refers to a woman between the ages of 35 and 64 years of age who is providing assistance and support to a spouse or relative unable to be self-sufficient in meeting his or her daily needs.

Burden of Care

Burden of care refers to the felt perception of potential and measurable degrees of physical and emotional strain incurred when providing care for another human being. In this study, burden of care was measured by the Caregiver Burden Scale (Zarit, Todd & Zarit, 1981).

Depression

Depression is the lack of positive regard and enjoyment that people generally derive from various aspects of their daily existence. This lack becomes clinically significant when it lasts for greater than 2 weeks and is measurable at a normatively established level. In this investigation, depression was measured via the use of the Beck Depression Inventory (Beck, 1978).

Life Satisfaction

Life satisfaction is defined as the cumulative expression of a person's overall pleasure or displeasure with life. In this study, life satisfaction was measured using the Life Satisfaction Inventory (Neugarten, Havighurst & Tobin, 1961).

Research Questions

The following research questions were developed for this investigation:

1. Are there significant relationships between the age of middle-aged female caregivers (35-64 years) and those caregivers' income, marital, and employment statuses, their perceptions of burden, their levels of depression, their satisfaction with life, the number of persons in their support system and the functional level of their dementia relative?
2. Are there significant differences between the middle-aged female caregivers when categorized into the age groups of 35-44, 45-54, and 55-64 and their income, marital, and employment statuses, their perceptions of burden, their levels of depression, their satisfaction with life, the number of persons in their support systems, and the functional level of the dementia relative?

CHAPTER III

METHODOLOGY

This research study was part of a larger, longitudinal, cross-sectional survey entitled, "Alzheimer's Disease and Related Disorders: A Longitudinal Study of Dementia Victims and Their Families" funded by the University of Utah Faculty Research Committee (Dale Lund, Ph.D., Principal Investigator) and the Intermountain West Long-Term Care Gerontology Center (funded by the Administration on Aging). The present study consisted of a descriptive survey that examined generational differences of middle-aged female caregivers of dementia patients 1 year after they had responded to an initial self-report survey.

Sample

Data were collected through self-report questionnaires completed by primary caregivers of dementia patients. These data were part of a 3-year, retrospective, cross-sectional survey of caregivers of Alzheimer's Disease patients. The data utilized in this study were from the second year of the longitudinal study. Caregivers were initially identified through mailing

lists from various local support groups. Investigators Lund and Caserta (1985) compiled a directory of 26 existing local support groups in Region VIII of Health and Human Services. This region included: Utah, Colorado, Wyoming, Montana, North Dakota, and South Dakota. Forty-eight additional support groups were identified by the Dallas Regional Office of the Administration on Aging and the Southwest Long-Term Care Gerontology Center. Region VI includes: Texas, Louisiana, Arkansas, Oklahoma, and New Mexico. Personal contacts resulted in 41 support groups being added to the list from Oregon, Washington, California, Nebraska, and New York.

In the first year of this study, 115 support group leaders received a letter that explained the research study. Fifty support group leaders sent their mailing lists, yielding a response rate of 43.5%. Confidentiality regulations set by the independent support groups meant some support group leaders were prohibited from releasing mailing lists to outside groups. Members in these groups were still able to participate in the study because their leaders distributed questionnaires either through the mail or at a meeting of the members. Some of the groups had been disbanded, thus contributing to the number not responding.

In the first year of the study, a total of 2,362 questionnaires was mailed over a 6-month period from June

1 to December 31, 1985. Subtraction of 24 undeliverable questionnaires yielded 2,338 who were assumed to have received a questionnaire. Of 1,112 returned questionnaires, 224 were not usable either because the Alzheimer's Disease patient was deceased, the responses were completed by nonkin professionals, or the survey returned was not complete enough to be considered valid or useful. The remaining 888 respondents were to be contacted in the second year of the study: 1986-87. Of these, 65 members of the Albuquerque support group requested not to be included in the second year of the study. Three support group leaders requested that they be allowed to disseminate the questionnaires at their support group meetings.

The 823 respondents of the second year were contacted in the manner previously described. Five hundred ninety-one questionnaires were returned. One hundred sixty-five questionnaires were excluded for the following reasons: (a) 21 questionnaires were returned to sender, (b) 106 Alzheimer's patients were deceased since the first survey, (c) 1 respondent was a nonkin paraprofessional, (d) 20 dementia patients had actually been dead at the time of the first data collection, but were not clearly identified as such by the caregiver respondent, (e) 7 refused to answer, (f) 4 were no longer the primary caregivers, and (g) 6 questionnaires were filled out by respondents other than the first respondent. A total of

426 valid questionnaires remained appropriate for the second year's study.

Data Collection Procedure

The data in this study were collected via a self-report questionnaire that was mailed either directly to the home of the prospective respondent or to the support group leader for dissemination to the caregiver in the respective support groups. The questionnaires were mailed to prospective respondents on a monthly basis from July 1, 1986 through January of 1987. The three support group leaders whose groups requested confidentiality received their follow-up questionnaires in one allotment each for distribution to the respondents of the previous year. These group members had chosen to have the leader retain a record of their identity and their matching identification numbers. This proved to be a problem when one group leader did not provide identification numbers on eight questionnaires. These questionnaires had to be matched with the previous year's sample by use of demographics, handwriting, and overall response to the qualitative questions. Handwriting proved to be the least reliable method of matching. Those respondents from the previous year whose questionnaires were neither returned within 1 month nor returned by the post office received a postcard reminder (Appendix A) regarding the study and need for their response.

Sample Criteria

A subsample of caregivers selected for the present study had the following characteristics:

1. Female,
2. 35-64 years of age, and
3. Caregiver to a dementia patient relative or primarily responsible for someone with this diagnosis.

Data Collection Returns

Data obtained from the second year of this study were used for this exploratory study. In the second year, 72% (N = 591) of the questionnaires were returned with 10% (n = 59) of these deleted for the following reasons: (a) 20 patients were deceased greater than 1 year, (b) 1 respondent was a paraprofessional, (c) 21 were returned marked "return to sender" by the postal service, (d) 7 of the previous year's respondents refused to answer the questionnaire, (e) 4 respondents were no longer the caregiver, and (f) 6 questionnaires were filled out by a respondent who had not participated in the previous year's study. Twenty-one respondents' Depression Inventory warranted a letter of concern over their stress level (Appendix B).

Measurement of Variables and Instruments

Demographics

Demographic data requested of respondents and utilized in this study pertained to the caregiver and to the dementia patient. Caregiver demographic data included: age, sex, relationship to the impaired family member or friend, annual household income from all sources, present marital status, percentage of time employed or lack of employment, and number of people providing care. Dementia patient demographics requested were: patient alive or deceased, age, sex, and marital status.

Beck Depression Inventory

The Beck Depression Inventory (BDI) has been described by Beck and Beamesderfer (1974) as a method of measuring the depth of depression. The BDI contains 21 items that measure symptoms and their degree of severity. Each of these categories relates to a particular and characteristic manifestation of depression. A 4-point self-rated ordinal scale is attached to the categories. Each category is totaled to reveal a total BDI score. This particular scale was devised by Beck who observed that (a) the number of symptoms, plus (b) the intensity of the distress were correlated with the severity of depression. Beck further noted that the frequency of the

depressive symptoms revealed a stepwise distribution along a continuum of nondepression to severe depression (Goldberger & Breznitz, 1982).

The reported internal consistency coefficient for the BDI is .86. Gallagher, Nies, and Thompson (1982), in a study focusing on reliability of the BDI with an elderly population in their late 60s, found the test-retest correlation coefficient to be .90. The coefficient alpha was .91, and the split-half index of reliability was .84.

There are extraneous considerations when using the BDI. Beck and Beamesderfer (1974) conducted a study to investigate the correlation of total BDI scores with such background variables as age, sex, and educational level, in order to determine if a biased relationship existed. These researchers reported no significant relationship between BDI scores and age. Being female, however, did lead to a higher score. Other researchers have reported that women evidence depressive symptoms more often than men (Hammen & Padesky, 1977; Teri, 1982).

Potential problems with use of the BDI in an elderly population were noted by Gallagher (1986). First, there is a potential language limitation for elderly individuals who may not have had an education beyond the eighth grade. The second problem is underreporting in an effort to "put their best foot forward." In contrast, depressive people overreport symptoms due to their generally negative self-

perceptions.

The BDI was used in this study; however, it was called the "Beck Inventory." The BDI is a standardized scale with 21 items and four potential answers to each item. Responses are listed, consistently as "0" to "3," in a vertical presentation. The questions relate to feelings, degrees of sadness, discouragement, failure, satisfaction, guilt, punishment, self-esteem, disappointment in self, suicidal ideations, crying, irritation or annoyance, decision-making, self-appraisal (appearance), sleep, tiredness, appetite, weight gain/loss, health concerns, and change in sexual drive. To score the BDI, the numbers of the choices circled are summed. The following score interpretations have been suggested by Beck (1978):

1. 0-9; normal range,
2. 10-15; mild range,
3. 16-19 mild-moderate range,
4. 20-29 moderate-severe depression, and
5. 30-63 severe depression.

If respondents' scores fell in either the moderately severe or severely depressed categories, and/or if they indicated they would like to kill themselves, or would kill themselves if they had the opportunity, their questionnaires were scrutinized as to their answers in sections related to: (a) marital status (for potential

support), (b) health, (c) caregiver assessment (especially under questions of control, leaving care to others, and sense of burden), (d) general life, (e) coping (especially problem-solving methods), and (f) support system presence and utilization. If the related areas were also indicative of personal distress, the respondents were sent a brief letter indicating concern about their emotional health and an offer was made to assist them in finding professional assistance in their area (Appendix B). Twenty-one letters of concern were sent to respondents. However, the researcher received no requests for information or help from these caregivers.

Functional Assessment of the Patient

The functional assessment of the patient was accomplished via the Functional Dementia Scale (FDS) (Moore, Bobula, Short, & Mischel, 1983). The FDS was designed to meet the needs of caregivers for a short and grammatically simple form devoid of medical terminology.

Six symptom areas are investigated with this instrument: (a) activities of daily living, (b) emotional lability, (c) memory and orientation, (d) paranoia and hallucinations, (e) agitation and wandering, and (f) judgment. The FDS is composed of a Likert-type scale grading responses to 20 statements about the physical, mental, and emotional functioning of the ill family

member. There are four possible choices to the Likert-scale with the following definition given for each of these choices in the heading: (1) = none or little of the time, (2) = some of the time, (3) = good part of the time, and (4) = most or all of the time.

The questions on the FDS relate to abilities to perform activities of daily living such as bathing, dressing, and arithmetic. Also measured are visual or auditory hallucination, control of bowel and bladder function, ability to unwittingly self-injure, destructive tendencies, catastrophic tendencies of suddenly hitting or shouting, untrue accusations, lack of awareness of personal limitations, confusion as to place, memory difficulties, sudden mood changes, and wandering day or night. At the end of the FDS, the respondent was asked to circle the two most difficult activities with which the caregiver had to cope.

Caregiver Assessment

The Caregiver Burden Scale (CBS) (Zarit et al., 1981) is composed of 22 items concerning feelings about caregiving. The questions were selected from clinical experience with caregivers and previous studies. Areas covered were those most frequently mentioned by caregivers: caregiver health, psychological well-being, finances, social life, and interpersonal relationship between the caregiver and impaired individual. The CBS

has an alpha reliability coefficient of .79.

The CBS is composed of 22 statement questions with five potential responses offered on a Likert-type scale. The responses range from "0" to "4" with correlating descriptors written below the numbers. Possible responses were: (0) = Never, (1) = Rarely, (2) = Sometimes, (3) = Quite frequently, and (4) = Nearly always. The caregiver burden score represents the summation of responses with a numerical range of 0-88.

Support Questions

The strain of caregiving is often reduced when other people make themselves available to the caregiver, as well as others' participation in meeting the numerous needs of the dementia patient (Zarit et al., 1980). The support question utilized in this survey asked caregivers to identify the number of people available to assist them in their caregiving activities.

Life Satisfaction Index-Z

The Life Satisfaction Index-Z (LSI-Z) is a measure of morale. It is a shorter instrument in comparison with the Life Satisfaction Index-A (LSI-A) from which it was developed. The Life Satisfaction Rating (LSR) was the original instrument from which the LSI-A and LSI-Z were derived (Neugarten, Havighurst & Tobin, 1961). The original LSR has five rating scales to measure five

components of life satisfaction: zest, resolution and fortitude, congruence between desired and achieved goals, positive self-concept, and mood tone (Wood, Wylie & Sheafor, 1969, p. 466). This direct self-report instrument requires the respondent to mark an "X" in one of three spaces for each of 13 statements. The spaces are marked, "agree," "disagree," and "?". Scoring is done by awarding a "2" for a "right" answer or high life satisfaction, a "1" for a question mark or no answer, and "0" for an incorrect answer or one indicating low life satisfaction. In tests of reliability, the LSI-Z had a test-retest reliability of .79 using the Kuder-Richardson formula 20 "coefficient alpha."

Data Analyses

The following descriptive statistics were utilized in data analyses: frequency distributions, modes, medians and means, ranges, and standard deviations. Pearson product-moment correlation coefficients were calculated to describe the magnitude and direction of the relationship between the variables, which provided both descriptive and inferential information about the variables under study.

After data were categorized in three age groups (cohorts), analyses of variance (ANOVA) were used to test the significance of the differences between means. This separated the data set into two components: (a) variability from the independent variables, and (b) all other

variability. The variation between groups is contrasted with variation within groups. When the F-ratio was significant, the Scheffe test for pairwise differences was used to determine which of the three middle-aged cohorts reflected the significant difference.

CHAPTER IV

RESULTS

The descriptive and inferential statistical analyses of the data pertaining to each of the research questions are presented in this chapter.

Statistics

Data were nominal, ordinal, and interval level. Questionnaires returned were initially processed by the researcher and then coded by the researcher and two staff members of the University of Utah Gerontology Center. Data were then analyzed with the Statistical Package for the Social Sciences (SPSS).

Data Analysis

Descriptive analyses included: frequency distributions, central tendencies, and standard deviations. Inferential statistics were computed through cross-tabulation tables, Pearson product-moment correlation coefficients and analysis of variance.

Caregiver Demographic Data

Demographic data relating to caregivers are presented in Table 1. The middle-aged, female caregivers (N = 187)

Table 1

Demographic Data for Female Caregivers

Variable	n	%
Age		
35-54	35	19.0
45-54	58	31.0
55-65	94	50.0
(Mean = 53; SD = 8)		
Relationship		
Daughter	113	60.4
Daughter-in-law	10	5.3
Sisters or in-laws	8	4.3
Spouse	54	28.9
Other	2	1.1
Marital Status		
Married	154	84.2
Never Married	9	4.8
Widowed	4	2.2
Divorced	14	7.5
Separated	2	1.1
Income		
Less than $10,000	10	5.3
$10,000 to $19,999	44	23.5
$20,000 to $29,999	34	18.2
$30,000 to $39,999	38	20.3
$40,000 to $49,999	18	9.6
$50,000 to $59,999	15	7.0
$60,000 to $69,999	7	3.7
$70,000 and above	12	6.4
(Mean = $30,000; SD = $20,000)		
Employment		
Not working	90	49.2
Part-time	24	13.1
Full-time	69	37.7

were between the ages of 35 and 65. The middle-aged category was subdivided into three decade age ranges: 35-44, 45-54, and 55-65. This categorization was done to determine if there were differences of experiences in caregiving based on age or cohort. A majority (50%) of the respondents fell into the oldest category (54-65 years), while a smaller number of caregivers were in the youngest (35-44 years) age range (19%). The mean age of the sample was 53 with a standard deviation of 8 years.

Caregivers in this study were most likely to be adult daughters (60%) with the next largest category of caregiver being the spouse (29%). The marital status of caregivers can also be reviewed in Table 1. Caregivers were predominantly married (82%) or divorced (8%), with the remainder either nonmarried, separated or widowed.

Income of the middle-aged of caregivers is presented in Table 1. Income for the largest number of these caregivers (n = 44) was in the lowest range ($10,000 - $19,000). The second largest group (n = 38) of middle-aged caregivers had incomes in the $30,000 - $39,000 range. The mean income for the sample was approximately $30,000 with a standard deviation of $20,000. Income ranged from below $10,000 to $70,000 and above. The majority of caregivers (over 50%) was employed, with 38% employed full-time.

Demographic Data for Patients

Demographic data describing the dementia patients in this study can be found in Table 2. The largest age grouping was 75-84 years (n = 65), and those 65-74 years of age composed the second largest group (n = 56). Both the oldest and the youngest groups of patients (45-54 and 95+ years of age) each had the smallest composition (n = 1). The mean patient age was 74 years with a standard deviation of 9.5 years. The majority of the patients was female (60%), married (48%) or widowed (43%), and institutionalized (44%). The primary diagnosis for these patients was Alzheimer's Disease (63%).

Research Question One

Research question one asked:

> Are there significant relationships between the age of middle-aged caregivers (35-64 years), and those caregivers' income, marital and employment statuses their perceptions of burden, their levels of depression, their satisfaction with life, the number of persons in their support systems, and the functional status of the dementia relative?

Pearson product-moment correlation coefficients (r) revealed that age correlated in varied significance with the demographic variables under study. There were strong, significant, negative relationships between caregiver age, and caregiver income (r = -.3605, p < .001) and employment (r = -.2248, $p \leq$ .002). As would be expected, there was a significant positive relationship between caregiver age and age of the impaired (r = .1571, p < .034)

Table 2

Demographic Data for Patients

Variable	n	%
Age		
45-54	1	.5
55-64	33	17.1
65-74	56	29.8
75-84	65	34.7
85-94	26	13.9
95+	1	.5
(Mean = 74, SD = 9.5)		
Gender		
Male	75	40.5
Female	110	59.5
Marital Status		
Married	90	48.6
Widowed	81	43.8
Separated	2	1.1
Divorced	11	5.9
Never Married	1	.5
Diagnosis		
Alzheimer's Disease	117	75.5
Other dementias	23	14.8
No formal diagnosis	15	9.7

(Table 3).

There was no significant correlation between caregiver age and the number of individuals in the social support system. There were also no significant correlations between caregiver age and functional level of patient, sense of burden, number of persons available for support, caregiver depression, or life satisfaction. These correlations ranged from r = -.1251 to .0549.

Research Question Two

Research question two asked:

> Are there significant differences between the middle-aged caregivers, when categorized into the three age groups of 35-44, 45-54, and 55-64 years of age, and their income, marital and employment statuses, their perceptions of burden, their levels of depression, their satisfaction with life, the number of persons in their support systems, and the functional status of the dementia relative?

The means, standard deviations, and ANOVAs for caregiver age cohorts and selected demographic variables are presented in Table 4. The mean income for the sample was $30,000, with a standard deviation of $20,000. ANOVA revealed a significant difference with income (F = 14.66, df = 2/172, $p < .001$) and age. Data from this study revealed that young and middle cohorts had similar incomes of nearly $35,000, while the mean income of the older cohorts was almost $20,000. The Scheffe pairwise analysis at the $p < .05$ level revealed a significant difference between the income of the oldest versus that of the

Table 3

Pearson Product-Moment Correlations and Crosstabulations Between Caregiver Age and Selected Caregiver Demographic Variables

Variable	Correlation with age	
Income	-.36***	
Employment status	-.22***	
	Married	Nonmarried
Young cohort	82.4%	17.6%
Middle cohort	29.9%	34.5%
Older cohort	51.9%	44.8%

Note. ***$p \leq .001$.

Table 4

Summary of Means, Standard Deviations, and Analysis of Variance for the Three Middle-Aged Cohorts and Selected Caregiver Demographics

Variable	Middle-Aged Cohort			df	F
	Young	Middle	Old		
Income					
Mean	$36,000	$34,000	$20,000	(2/173)	14.66**
SD	10,000	10,000	10,000		
Employment					
Mean	FT[a]	FT	FT	(2/180)	3.89*
SD	FT	FT	FT		
	Chi-square				
	Young	Middle	Old		
Married	82%	30%	50%		

Note. [a] FT = full-time; *$p < .05$; **$p < .01$.

youngest and middle cohorts.

The mean score for employment (.885) indicated that most caregivers were not working. The standard deviation (.92) was indicative of the caregiver either working part-time or not working outside the home. The ANOVA indicated a significant difference between age cohorts and employment status (F = 3.89, df = 2/180, $p < .0222$). The oldest cohort was most likely to be not employed outside the home, while the young and middle cohorts were more often employed at least part-time outside the home. The Scheffe pair-wise analysis at the $p < .05$ level reflected a significant difference in employment status between the youngest and oldest cohorts.

There were no significant differences between the three age cohorts and functional level of the dementia relative, the caregivers' sense of burden, the number of persons in the support system, caregivers' depression, or life satisfaction (Table 5).

The mean score for functional dementia indicated that the young cohort of caregivers cared for patients who were moderately dysfunctional with a mean score of 53 and a standard deviation of 14. The middle cohort of caregivers cared for the most dysfunctional patients with a mean functional score of 55 and a standard deviation of 15. Oldest caregivers cared for the least dysfunctional patients with a mean functional score of 50 and a standard

Table 5

Summary of Means, Standard Deviations, Observed/Possible Ranges and Analysis of Variance for Middle-Aged Caregivers and Selected Study Variables

Variables	Middle-Aged Cohorts			df	F	Range	
	Young	Middle	Old			Observed	Possible
Functional Level							
Mean	58.9	55.3	50.1	(2/163)	2.30	25-80	20-80
SD	13.5	15.4	12.8				
Burden							
Mean	41.0	36.8	37.7	(2/154)	.61	2-75	0-88
SD	14.8	17.3	17.0				
Number in Support System							
Mean	4.0	3.8	4.3	(2/174)	.85	0-30	0-99
SD	4.7	3.1	4.4				
Beck Depression Inventory							
Mean	9.4	8.6	9.8	(2/178)	.53	0-36	0-63
SD	6.6	8.6	6.3				
Life Satisfaction Inventory							
Mean	17.2	18.3	16.7	(2/181)	1.00	2-26	0-26
SD	5.5	6.9	6.3				

deviation of 13.

The highest mean score for burden was carried by the youngest caregivers at 41, with the lowest standard deviation (15). The oldest and middle cohort of caregivers both reported least burden with a mean score of 37 and a standard deviation of 17.

Regarding available support systems, there were no significant differences in the standard deviations of each of the three cohorts of middle age. The mean scores indicated a support system of four persons available to the caregiver with a standard deviation between three and four.

The BDI mean scores and standard deviations indicate that the oldest cohort were borderline in being mildly depressed (mean = 10), with the range for mild depression being 10-15. Means for the young and middle cohorts were 9 and 10, respectively. The standard deviations for these two cohorts (7 and 9, respectively) suggest the possibility that some individuals experienced mild to moderate depression (range for category = 16-19).

Although not statistically significant, the middle cohort had the greatest amount of life satisfaction with a mean score of 18, and a standard deviation of 7. Oldest and youngest caregivers showed similar amounts of life satisfaction with mean scores of 17, and standard deviations of 6.

Summary

Results from this study demonstrated that income and employment were significantly and negatively correlated with age of the caregiving sample. Data analyses revealed that manipulation of the data into cohorts by age did not alter the perception or experience of caregiving based upon outcome indicators used in this study.

CHAPTER V

DISCUSSION, LIMITATIONS, AND RECOMMENDATIONS

The results from this study will be addressed as they relate to the research questions developed.

Discussion

Relationship Bewteen Age and Variables Associated with the Caregiving Experience

The initial purpose of this study was to determine whether a relationship existed between age and measurable variables associated with the caregiving experience. Correlations between income/employment and age suggest that with middle-aged caregivers, a significantly reduced income could be expected to add to the stress of caregiving. Since middle-aged caregivers were not compared to young (less than 35 years of age) and old caregivers (over 65 years of age), it is not possible to state definitively how much effect the lack of income had on their stress. The relationship between income and stress was not one of the variables under study in this investigation.

Differences Between Three Age Cohorts and Specified Variables

Caregivers were divided into three age cohorts of middle-age in order to ascertain possible differences in caregivers' experiences that could have implications for developmental differences in caregiving. Based upon the variables measured (i.e., caregiver burden, functional level of the dementia patient, life satisfaction, depression, and number of people in the caregiver's support system), there were no significant differences between the three cohorts of middle-age.

One explanation for the failure to identify significant differences between age and perceived aspects of caregiver burden and other variables assessed is that elements of caregiving are perceived in similar ways by middle-aged women in support groups. Evidence from this investigation indicates that caregiving has a universality that may not be directly related to age. Rather, it may be related to the context within which the caregiver operates. The lack of statistically significant differences among the three cohorts on perceptions of caregiving does raise questions concerning the questionnaire and methodology employed in this investigation.

Reflected Developmental Theories

Developmental theorists support the concept that middle-age is a period during which men and women are both

at a stage when nurturance of others is a primary concern. For example, Levinson (1978) theorized that men in their mid-40s are reevaluating their commitment to the world of work and are beginning to reemphasize familial and relational bonds. Similarly, women are attempting to integrate affectional and instrumental aspects of their personality (Frieze, 1978).

Middle-aged women may be anticipating a return to the workforce with an emphasis on self-development in contrast with their role as a parent. When faced with caregiving for an aging relative, conflict between self-development and a nurturing role may occur. Caregiving incorporates many instrumental tasks while also calling upon the female caregiver's more affectional attributes. Instrumental tasks may offer little in emotional rewards unless they are bolstered by the husband's renewed interest in family matters.

This interest in generativity (Erikson, 1950, 1968, 1980) occurring during the mid 30s to age 60 involves a renewed awareness of internal tenderness. During middle age, men reemphasize a personalized interest in the family in place of provisional concerns for the family's welfare.

Both male and female middle-aged parents experience freedom from involvement in the functional and emotional issues of child care. Husband and wife can experience renewed personal growth. This renewal, important to

reconvergence and strengthening of the adult bond after raising children, could be utilized for another type of caregiving, parent-care.

Of the developmental theorists, Havighurst (1972) most clearly ties developmental theory with society's responsibility to find methods of dealing with an individual's developmental needs. This theory most easily facilitates the introduction of caregiving into the developmental life stage of middle-age. Havighurst (1972) also points to society's obligation to offer a response to this newly-recognized, middle-aged responsibility.

The findings from this study failed to identify differences in the psychosocial aspects of caregiving despite a 30-year developmental difference in the life experiences of the middle-aged cohort. However, the survey questionnaire used in this study did not include developmentally-focused items. Midlife markers such as age, age of children, signs of midlife crisis, decline of child development demands, menopause, and community involvement (Brooks-Gunn & Kirsh, 1984) should be systematically studied as they relate to the caregiving role. Results from this study did show, for the most part, that caregivers find resources that allow them to bear the burden, however hard it may be for them.

Sample Characteristics

The characteristics of this sample revealed that the greatest number of caregivers were in the older cohort (55-65) of middle-age while the mean age (53) fell into the middle cohort. A predominance of middle-aged caregivers was also found in studies by Cantor (1983), Stoller (1983), and Brody (1981) versus young or old caregivers. In the present study, most caregivers were married and lived in metropolitan areas. Using a sample of caregivers from a larger metropolitan area where support groups are available may explain why this sample had a high median income of $30,000 - $39,000. Almost 50% of the caregivers were unemployed. Perhaps being unemployed was a primary factor in the initial assumption of caregiving responsibilities. As would be expected, there were half as many caregivers (n = 35, 19%) in the youngest cohort as in the middle (n = 58, 31%) and older (n = 94, 50%) cohorts. The middle cohort had the lowest depression and highest life satisfaction scores.

Half of the caregivers were employed either part-time or were totally unemployed. These findings might suggest that having to give care conflicted with employment. However, interpretations of these correlations must be balanced by the fact that a greater number of caregivers were older, would not have customarily remained in the workforce, and would have been living on reduced incomes

of their retiring or retired spouses, regardless of whether they had assumed caregiving responsibilities.

Limitations

The original intent of this study was to determine if there were significant age relationships associated with the experience of caregiving and if age differences were reflected in selected variables associated with the caregiving role. Few significant correlations or differences were identified, thus raising questions regarding the design and methodology employed in this study, as well as the research questions themselves.

A primary methodological concern involves the failure to target the questionnaire toward detection of developmental issues. There are also significant concerns regarding the methodology employed to measure burden and the scale utilized to detect depression.

In this investigation, the research questions were not developed prior to the development of the questionnaire due to the fact that the present investigation was part of a larger study already in progress. Very judicious placement of new questions or instruments was required in order to keep the second year's study true to its original form. Thus, failure to identify age-related differences may well have resulted from the structure of the questionnaire, rather than from true absence of developmental variations in this sample.

Another limitation of this study focuses attention on the characteristics of contemporary women. The exploration of more diverse developmental paradigms reflective of "the woman of the 80s" and her unique approach to the world (Brody, 1981; Masciocchi et al., 1984; Neugarten, 1977; O'Rand & Henretta, 1982) might have been facilitated by more pointed, probing questions related to role choices. It would have been helpful to measure whether women who chose to work prior to childbearing had a different response to the caregiving role than those who had families, were preparing to return to work, and were then faced with parent-care. A question that arises is whether those women who chose to be "off-time" (Neugarten, 1977) find conflict when parent-care requires that they be "on-time." Clearly, survey designs do not facilitate use of probing or open-ended questions.

While use of support groups from a large number of states to obtain information presents researchers with a larger data base, the data gathered are biased in that participants were already self-selected by reason of their participation in the support group. One would wonder, therefore, about the characteristics of those caregivers who do not naturally gravitate to support groups. Lockery (1985) noted that minority family members rely on their own resources for the multidimensional needs of their elderly family members. The methcdology employed in this

investigation spoke predominantly to Caucasian, middle-to-upper class, self-help oriented caregivers in the Western United States. For example, nothing was learned about such minority groups as American Indian, Black, Chinese, Guamanian, Japanese, Latino, Philipino, and Samoan (Lockery, 1985).

This investigator experienced further limitations when the relationship of caregiver to parent was not controlled. This resulted in ex-spouses, daughters, daughters-in-law, and other relatives being studied within this one middle-aged group. No specific delineation was made as to where the patient and caregiver lived. Residence would potentially impact the caregiving experience. Furthermore, there was a mix of time caregivers spent with the patient, as well as the percent of responsibility perceived. None of these variables was controlled in this study.

The population surveyed in this study consisted primarily of middle-class Caucasian caregivers. Therefore, results can only be generalized to a population of similar caregivers. Professionals engaged in planning social, nursing, and medical needs of caregiving families must consider economic and racial realities not addressed in this study.

Recommendations

The focus of the literature review, the data selected from the larger study, and the analyses were based upon experiences of middle-aged, female caregivers. Differences were examined based on whether the respondent fell into the youngest, middle, or oldest age category of middle age. Utilizing middle-aged developmental issues as a conceptual framework, a more appropriate focus for this study might be those elements central to the developmental stage of middle life. Examples of variables appropriate for a study of this nature would be: (a) career shifts made, hoped for, and/or changed by caregiving; (b) children leaving/reentering the home, (c) "empty-nest" experiences; (d) time between last child in home and becoming a caregiver; (e) degree of marital, emotional, and financial satisfaction, (f) preparation for retirement; (g) involvement in social, recreational, and civic organizations or groups; (h) menopausal experiences; and (i) potential heightening of menopausal problems by the caregiving role. Studying ways in which the caregiving role has altered both the experience and the enactment of middle-age roles would be appropriate for a study of this nature.

Erikson's (1980) theory of stages of psychosocial development proposes that a sense of generativity is the primary focus of middle age. Generativity involves not

only procreation, but the nurturance of the child brought forth from the couple's union. It would be interesting to ascertain whether assumption of a caregiving role interferes with the mothering role by investigating variables related to children such as school grades, school activities, relationships with friends, relationships within the family, and other social activities. For those caregivers who were grandparents, it would be interesting to determine whether the caregiving role had interfered with the role of being a grandparent or added a new dimension. Grandparents could be, potentially, modeling a new family role. Questions pertaining to time spent with grandchildren, level of perceived enjoyment, frequency of visits with grandchildren, and whether caring for a dementia patient affected the child's visitation would shed light upon questions regarding changes in the grandparent-grandchild bond.

It would also be valuable to investigate the impact that caring for a dementia patient has on other middle-age female roles. Examples of these roles might be spouse, re-entry worker, the single-working woman, and volunteers.

Recommendations for Improvements in the Instrumentation

In subsequent investigations, a clearer distinction needs to be made between subjective and objective burden. Montgomery, Gonyea, and Hooyman (1985) determined that

subjective burden is a determinant of caregiver characteristics and objective burden relates to the type of tasks performed. In other words, tasks that require large amounts of time or geographical restriction of the caregiver create more objective burden. Research by Poulshock and Deimling (1984) corroborated these findings. It would be valuable to control for the caregivers' tasks in order to gain more information on the impact of specific tasks upon the aspects of the caregiving experience under study.

The BDI is a well-respected and statistically-sound instrument. Other measures of depression should, however, be explored. In an analysis of objective and subjective measurements of burden, Poulshock and Deimling (1984) found that the Zung Depression Scale (1972) offered the most consistent measurement of depression. Another instrument, the "Affect-Balance Scale," by Bradburn (1969) offers the advantages of being short, configured in "yes" and "no" responses, and in either self-report or interview formats. The Center for Epidemiological Studies Depression Scale (CES-D), developed by the National Institute of Mental Health and reported by Frerichs, Aneshensel, and Clark (1980) consists of 20 items that assess aspects of depression such as: mood, feeling, and behavior encountered over the previous week. Weights are assigned to the items based on the length of their duration (e.g., a

few days versus a week).

A number of standardized questionnaires that assess various aspects of caregiving might be considered for subsequent studies of this nature. The "Ease of Role Transition" tool, developed by Miller (1976a), focuses on role changes and adjustment. This tool has the advantage of being short, but it is not self-administered. Another assessment tool, "Anticipatory Socialization" (Miller, 1976b), has similar advantages and disadvantages.

A tool developed by the National Council on Aging (1975) entitled "Volunteer Participation" is very simple and although it is designed to include a personal interview, it could potentially be self-administered. Kahana and Kahana's (1975) "Coping with Stress" inventory utilizes very short answers and measures coping versus environmental factors. However, its usefulness in a survey design is questioned due to the necessity of a paper and pencil methodology that requires administration by an outside party. The need for an outside administrator may be an indication that this test is too sophisticated for the caregivers. It would also add to the time it takes to complete a survey questionnaire. Respondents would not be able to answer the questions at their leisure.

CHAPTER VI

SUMMARY AND IMPLICATIONS

Summary

The results of this study failed to demonstrate a significant relationship between age, depression, life satisfaction, burden, and number of people in support systems. Differences between the middle-aged cohorts were not identified as they related to the independent variables mentioned above. Some demographic variables did show some significant positive and inverse correlations. Yet, a question remains. Do middle-aged caregivers not in support groups experience age-related differences in response to caregiving? Results from this study are not generalizable to the general caregiving population due to the methodology of surveying only support group members.

Implications for Future Research

Based on the findings of this study, it is suggested that future research should be directed toward refinement and operationalization of a middle-aged conceptual model of caregiving. This would allow the researcher to determine the degree to which middle-age developmental issues are made more problematic by caregiving. Mecha-

nisms used to resolve developmental conflicts should be examined and difficulties in expression of affectional and instrumental aspects of middle-age by both men and women in caregiving households should be considered. Future studies could also compare the experiences of caregivers in support groups to the experiences of caregivers not in support groups. It is also recommended that an effort be made to determine potential impediments to parenting and grandparenting brought about by caregiving with special emphasis on the effects upon children and grandchildren. Finally, caregivers should be probed for the effects that caregiving has on human nurturance and need fulfillment.

As mentioned in Chapter V, alternative instruments should be considered that would assist the caregiver in expressing more comprehensive aspects of burden. In addition to assessing subjective and objective categories of burden, it would be appropriate to consider the specific areas of burden (e.g., disruptions in affectional ties, decision-making, physiological deprivation, physical weakness, lack of nursing knowledge, existence of previous emotional difficulties with the patient, and previous abuse of a caregiver).

It is recommended that one of the following depression inventories be considered for use in subsequent studies of this nature: (a) the Zung Depression Inventory (1972), (b) the CES-D Scale developed by the National

Institute of Mental Health (Frerichs et al., 1980), and/or (c) the Bradburn (1969) "Affect-Balance Scale." Furthermore, it is recommended that other standardized instruments like those mentioned in Chapter V (Chapin, 1939) Kahana & Kahana, 1975; Miller, 1976a,b; National Council on Aging, 1975) be considered in order to identify more detailed and comprehensive data on caregiver burden. Finally, it is suggested that questions developed to ascertain effects of caregiving on middle-aged developmental roles and issues would be best constructed on a Likert-scale format that would facilitate identification of various degrees of expression.

Implications for Nursing

Health care providers should always be aware of the developmental needs and individuality of both caregivers and patients. Even within the various developmental stages, psychosocial needs vary considerably. Nurses need to gather detailed information about the caregiver's life in order to develop strategies that might reduce burden and assist the caregiver in meeting his or her own needs. Examples of the type of information that would be useful relate to household organization, amount of role conflict between childrearing and parent care, employment issues, how relationships are affected, and emotional realities of the caregiver-patient relationship, to name only a few.

Health care workers must recognize that the care-

giver's most pressing need may not be for assistance with care provision. Rather, the most pressing need may be for the presence of another with whom the caregiver can share the emotional turmoil of living with a demented patient. The caregiver often manifests a need to be validated as a human being.

In order to legitimize the government bureaucracy surrounding care of dementia patients, nurses need to develop advocacy programs for the recognition of parent-care as a legitimate problem with serious personal and societal implications. Nurses must continue to sensitize themselves to parent-care stress and assist in documenting problems. Additionally, nurses must serve as family advocates and assist family members in identifying resources and obtaining support needed by the primary caregiver.

APPENDIX A

REMINDER POSTCARD[1]

[1] Reprinted with permission of Dale Lund, Ph.D.

Dear Caregiver:

I am writing on behalf of the Research Team at the University of Utah. We have sent a questionnaire to you regarding your experiences in the care of an elderly relative. We are very interested in your experiences and would appreciate your filling out the questionnaire and returning it to us.

If you have lost your questionnaire, we would be happy to send you another one. If you have a problem answering the questions, please feel free to contact us. We would be happy to assist you. We want to compare the experiences of caregivers over a 2-year period. This has not been done by any researchers in the past. Your assistance in this project will greatly enhance our findings.

Sincerely,

Dale Lund
Gerontology Center
University of Utah
Salt Lake City, UT 84102
(801) 581-8198

APPENDIX B

LETTER TO DEPRESSED CAREGIVERS[2]

[2] Reprinted with permission of Dale Lund, Ph.D.

Dear _____:

The caregiver's questionnaire which you recently filled out and mailed back to the Gerontology Center at the University of Utah has been received. We would like you to know that we really appreciate your assistance with this project. As we reviewed your experiences as a caregiver, it seemed that you are experiencing a fair amount of stress at this time. If things do not improve for you soon, we would like to encourage you to locate appropriate services in your local area to aid in supporting you at this particularly difficult time. If you would rather, you could contact Dr. Dale Lund or Marge Sobczak and we could help you locate services. Please let us know if we can be of any assistance.

Sincerely,

Dale Lund

REFERENCES

American Psychiatric Association (1975). A psychiatric glossary (4th ed.). Washington, DC: Author.

American Psychiatric Association (1987). Diagnostic and statistical manual of mental disorders (DSM III) (3rd ed., rev.). Washington, DC: Author.

Aneshensel, C.S., & Frerichs, R.R. (1983). Stress, support and depression: A longitudinal causal model. Journal of Community Psychology, 10, 363-376.

Baltes, P.B., Reese, H.W., & Lipsett, L.P. (1980). Life-span developmental psychology. In M.R. Rosenzweig & L.W. Porter (Eds.), Annual review of psychology (pp. 65-110). Palo Alto: Annual Reviews.

Barrera, M. (1981). Social support in the adjustment of pregnant adolescents: Assessment issues. In B.H. Gottlieb (Ed.), Social networks and social support (pp. 69-96). Beverly Hills: Sage.

Beck, A.T. (1978). Depression inventory. Philadelphia: Center for Cognitive Therapy.

Beck, A.T., & Beamesderfer, A. (1974). Assessment of depression: The depression inventory. In P. Pichot (Ed.), Psychological measurements in psychopharmacology. Modern problems in pharmacopsychiatry (pp. 151-169). Basel, Switzerland: Korger.

Becker, J. (1980, September). Depression research 1970-1980: Old wine in new bottles? Paper presented at the 88th Annual Convention of the American Psychological Association, Montreal, Canada.

Boyd, J.H., & Weissman, M.M. (1982). Epidemiology. In E.S. Paykel (Ed.), Handbook of affectional disorders (pp. 109-125). New York: Guilford.

Bradburn, N.M. (1969). Affect-balance scale. In D.J. Morgan & W.A. Peterson (Eds.), Research instruments in social gerontology. Vol. I: Clinical and social psychology (pp. 236-237). Minneapolis: University of Minnesota Press.

Brody, E. (1981). "Women in the middle" and family help to older people. The Gerontologist, 21, 471-480.

Brooks-Gunn, J., & Kirsh, B. (1984). Boundaries of midlife. In G. Baruch, & J. Brooks-Gunn (Eds.), Women in midlife (pp. 1-32). New York: Plenum.

Cantor, M.H. (1983). Strain among caregivers: A study of experience in the United States. The Gerontologist, 23, 597-604.

Cath, S.H. (1972). The geriatric patient and his family: The institutionalization of a parent: A nadir of life. Journal of Geriatric Psychiatry, 5, 25-46.

Chapin, F.S. (1939). Social participation scale. In D.J. Mangen & W.A. Peterson (Eds.) (1982), Research instruments in social gerontology. Vol. II: Social roles and social prticipation (pp. 24-25). Minneapolis: University of Minnesota Press.

Cutler, L. (1985, Fall). Counseling caregivers. Generations, 53-57.

Ebersole, P., & Hess, P. (1985). Toward healthy aging: Human needs and nursing response. St. Louis: Mosby.

Erikson, E. (1950). Childhood and society. New York: Norton.

Erikson, E. (1968). Identity: Youth and crisis. New York: Norton.

Erikson, E. (1980). Identity and the life cycle. New York: Norton.

Fitting, M.D., Rabins, P.V., & Lucas, M.J. (1984, November). Caregivers for dementia patients: A comparison of men and women. Paper presented at the 37th Annual Scientific Meeting of the Gerontological Society of America, San Antonio, TX.

Folstein, M.F., & McHugh, P.R. (1978). Dementia: Syndrome of depression. In R. Katzman, R.D. Terry, & K.L. Bick (Eds.), Aging, Vol. 7: Alzheimer's disease: Senile dementia related disorders (pp. 87-93). New York: Raven.

Folstein, M., Powell, D., & Breitner, J. (1983). Biological aspects of Alzheimer's disease: The cognitive pattern of familial Alzheimer's disease (Banbery Report No. 15). Cold Spring Harbor, NJ: Cold Spring Harbor Laboratory.

Franks, J. (1974). Persuasion and healing (Rev. Ed.). New York: Schocken.

Frerichs, R.R., Aneshensel, C.A., & Clark, V.A. (1980, June). Prevalence of depression in Los Angeles

County. Paper presented at the Society of Epidemiological Research, Minneapolis, MN.

Fries, J.F., & Crapo, L.M. 91986). The elimination of premature disease. In K. Dychtward (Ed.), Wellness and health promotion for the elderly (pp. 19-37). Rockville, MD: Aspen.

Frieze, I.H. (1978). Women and sex roles. New York: Norton.

Gallagher, D. (1986). The Beck Depression Inventory and older adults: Review of its development and utility. In T.L. Brink, Clinical gerontology (p. 149). New York: Haworth.

Gallagher, D., Nies, G., & Thompson, L.W. (1982). Reliability of the Beck Depression Inventory with older adults. Journal of Consulting and Clinical Psychology, 50, 152-153.

Goldberger, L., & Breznitz, S. (1982). Handbook of stress: Theoretical and clinical aspects. New York: The Free Press.

Goldhaber, D. (1986). Life-span human development. New York: Harcourt, Brace and Jovanovich.

Gottlieb, B.H. (1985). Social networks and social support: An overview of research, practice, and policy implications. Health Education Quarterly, 12 (1), 5-22.

Grad, J., & Sainsbury, P. (1963). Mental illness and the family. Lancet, 1, 544-547.

Gurland, B. (1958). The comparative frequency of depression in various adult age groups. Journal of Gerontology, 31, 273-278.

Hammen, C., & Padesky, C. (1977). Sex differences in the expression of depressive responses on the Beck Depression Inventory. Journal of Abnormal Psychology, 86, 609-614.

Havighurst, R.J. (1972). Developmental tasks and education. New York: David McKay Company.

Hibbard, J. (1985). Social ties and health status: An examination of moderating factors. Health Education Quarterly, 12 (1), 23-34.

Horn, R. (1970). Psychosexual problems in the middle years. Clinical Obstetrics and Gynecology, 13, 746-755.

Horowitz, A. (1985). Family caregiving to the frail elderly. In C. Eisdorfer (Editor in Chief), M.P., Lawton & G.L. Maddox (Special Volume Editors), Annual review of gerontology and geriatrics (pp. 194-246). New York: Springer.

Johnson, C.L., & Irvin, F.S. (1983). Depressive potentials: Interface between adolescence and midlife transition. In H.L. Morrison (Ed.), Children of depressed parents: Risk identification and intervention (pp. 115-137). New York: Grune and Stratton.

Kahana, E., & Kahana, B. (1975). Coping with stress. In D.J. Mangen & W.A. Peterson (Eds.), Research instruments in social gerontology. Vol. I: Clinical and social psychology (pp. 161-162). Minneapolis: University of Minnesota Press.

Levinson, D.J. (1978). The seasons of a man's life. New York: Knopf.

Lockery, S.A. (1985, Fall). Care in the minority family. Generations, 27-29.

Long, J., & Porter, K.L. (1986). Multiple roles of midlife women: A case for new directions in theory, research, and policy. In F.A. Boudreau, R.S. Sennott, & M. Wilson (Eds.), Sex roles and social patterns (pp. 109-160). New York: Praeger.

Longe, M.E. (1986). Hospitals and health promotion for older adults. In K. Dychtward (Ed.), Wellness and health promotion for the elderly (pp. 275-287). Rockville, MD: Aspen.

Lund, D., & Caserta, M. (1985). Directory of Alzheimer's disease and related disorders support groups in H.H.S. region VIII. Salt Lake City: Intermountain West Long-Term Care Gerontology Center, University of Utah.

Mace, N., & Rabins, P. (1981). The 36 hour day. Baltimore: Johns Hopkins University Press.

Marples, M. (1986, October). Helping family members cope with a senile relative. The Journal of Contemporary Social Work, 490-498.

Masciocchi, C., Thomas, A., & Moeller, T. (1984). Support for the impaired elderly: A challenge for family caregivers. In W. Quinn, & G.A. Hughston (Eds.), Independent aging from a social systems perspective (pp. 115-132). Rockville, MD: Aspen.

McLoughlin, M., Shryer, T., Goode, E., & McAuliffe, K. (1988, August 8). Men versus women. U.S. News and World Report, 55.

Miller, B.C. (1976a). Anticipatory socialization. In D.J. Mangen & W.A. Peterson (Eds.), Research instruments in social gerontology. Vol. II: Social roles and social participation (p. 106). Minneapolis: University of Minnesota Press.

Miller, B.C. (1976b). Ease of role transition. In D.J. Mangen & W.A. Peterson (Eds.), Research instruments in social gerontology. Vol. II: Social roles and social participation (p. 99). Minneapolis: University of Minnesota Press.

Mitchell, R.E., & Moos, R.H. (1984). Deficiencies in social support among depressed patients: Antecedents or consequences of stress? Journal of Health and Social Behavior, 25, 438-458.

Montgomery, R.J.V., Gonyea, J.G., & Hooyman, N.R. (1985, January). Caregiving and the experience of subjective and objective burden. Family Relations, 19-25.

Moore, J.T., Bobula, J.A., Short, T.B., & Mischel, M. (1983). A functional dementia scale. The Journal of Family Practice, 16 (3), 499-503.

National Council on Aging (1975). Volunteer participation. In D.J. Mangen & W.A. Peterson (Eds.), Research instruments in social gerontology. Vol. II: Social roles and social participation (pp. 472-475). Minneapolis: University of Minnesota Press.

Neugarten, B.L. (1977). Personality and aging. In J.E. Birren & K.W. Schaie (Eds.), Handbook of the psychology of aging (pp. 426-498). New York: Van Nostrand Reinhold.

Neugarten, B.C., Havighurst, R.J., & Tobin, S.S. (1961). Life satisfaction index. In D.J. Mangen & W.A. Peterson (eds.), Clinical and social psychology. Research instruments in social gerontology. Vol. I: Clinical and social psychology (p. 237). Minneapolis: University of Minnesota Press.

Niederehe, G., & Fruge, E. (1984). Dementia and family dynamics: Clinical research issues. Journal of Geriatric Psychiatry, 17 (1), 21-56.

Niederehe, G., Fruge, E., Woods, A.M., Scott, J.L., Volpendesta, D., Nielsen-Collins, K.E., Moye, G., Gibbs, H., & Wiegand, G. (1983, November). Caregiver stress in dementia: Clinical outcomes and family considerations. Paper presented at the Symposium on Caring for Dementia Patients: Caregiver Burden and Prospects for Effective Intervention (26th Annual Scientific Meeting of the Gerontological Society of America).

O'Rand, A., & Henretta, J.C. (1982). Women at middle age. Developmental Transition Annals, 464, 57-64.

Ory, M.G., Williams, T.F., Emr, M., Lebowitz, B., Rabins, P., Salloway, J., Sluss-Randbough, T., Wolff, E., & Zarit, S. (1985). Families, informal supports and Alzheimer's disease: Current research and future agenda. Research on Aging, 7, 623-644.

Poulshock, S.W., & Deimling, G.T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 39 (2), 230-239.

Rakowski, W., & Clark, N. (1985). Future outlook: Caregiving and care receiving in the family context. The Gerontologist, 25 (6), 618-623.

Schaefer, C., Coyne, J.C., & Lazarus, R. (1981). The health-related functions of social support. Journal of Behavioral Medicine, 4 (4), 381-406.

Scott, J.P., Roberto, K.A., & Hutton, J.T. (1986). Families of Alzheimer's victims: Family support to the caregivers. Journal of the American Geriatric Society, 34, 348-354.

Smith, N.L., & Kinsbourne, M. (1977) (Eds.). Aging and dementia. New York: Spectrum.

Stoller, E.P. (1983). Parental caregiving by adult children. Journal of Marriage and the Family, 45, 851-858.

Teri, L. (1982). The use of the Beck Depression Inventory with adolescents. Journal of Abnormal Child Psychology, 10, 277-284.

Treas, J. (1977). Family support systems for the aged: Some social and demographic considerations. The Gerontologist, 17, 486-491.

Turner, J.S., & Helms, D.B. (1979). Life span development. Philadelphia: Saunders.

Turner, R.J., & Noh, S. (1982, September). Social support, life events and psychological distress: A three-wave panel analysis. Presented at the American Sociological Association Meeting, San Francisco, CA.

U.S. Bureau of the Census (1982). Biennial censuses of the population, 1900-1980 and projections of the population of the United States: 1982-2050 (advance report). In Current population reports (series P-25, No. 922). Washington, DC: Author.

U.S. Senate Special Committee on Aging (1983) (in conjunction with the American Association of Retired Persons). Aging America: Trends and projections (PL 3377-584). Washington, DC: U.S. Government Printing Office.

Wang, H.S. (1977). Organic brain syndrome. In P. Ebersole & P. Hess, Human needs and nurse response. (p. 669). St. Louis: Mosby.

Weiler, P.G. (1986). Education and training in wellness for health care providers. In K. Dychtwald (Ed.), Wellness and health promotion for the elderly (pp. 71-86). Rockville, MD: Aspen.

Wilcox, B.L. (1981). Social support, life stress, and psychological adjustment: A test of the buffering hypothesis. American Journal of Community Psychology, 9 (4), 371-386.

Wilken, C.S. (1986, July/August). The application of recognized family therapies in working with specialized needs of aging families. Nursing Homes, 30-34.

Wood, V., Wylie, M.L., & Sheafor, B. (1969). An analysis of a short self-report measure of life satisfaction: Correlation with rater judgments. Journal of Gerontology, 24, 465-469.

Zarit, J.M., & Zarit, S.H. (1982, November). Measuring burden and support in families with Alzheimer's disease elders. Paper presented at the Thirty-Fifth Annual Meeting of the Gerontological Society of America, Boston, MA.

Zarit, S.H., Orr, N.K., & Zarit, J. (1985). The hidden victims of Alzheimer's disease: Families under stress. New York: University Press.

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feeling of burden. The Gerontologist, 20, 649-675.

Zarit, S.H, Todd, P.A., & Zarit, J.M. (1981). Family relationships and burden in long-term care. Paper presented at the Annual Scientific Meeting of the Gerontological Society of America, Toronto, Canada.

Zung, W.W.K. (1972). The depression status inventory: An adjunct to the self-rating depression scale. Journal of Clinical Psychology, 28, 539-542.